A qualitative exploration of HIV stigma and its impact on accessing healthcare


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Background and aim

- Thanks to medical advances in the treatment of HIV, people living with HIV (PLWH) on antiretroviral therapy have a life expectancy approaching that of the general population.
- Despite this, living with HIV remains challenging due to its HIV-related stigma, which has a negative impact on mental health, quality of life, and access to treatment for PLWH.
- Between March 2020 and January 2021, a cross-sectional survey study using a validated 12-item HIV stigma scale was completed by 5,563 PLWH enrolled in the Swiss HIV Cohort Study (SHCS). HIV stigma was present across all demographic groups and disclosure concerns were reported in >80% of participants. However, being able to talk about it, that can provide a deep understanding of stigma experience or coping strategies.
- The aim of the current qualitative study is to explore the way PLWH perceive and experience HIV stigma in their lives, including when accessing healthcare in Switzerland. Here, we present the first stage of analysis.

Methods

- Patient and Public Involvement (PPI) was an integral part of this study, a collaboration between qualitative researchers, clinicians, and a patient expert.
- Between 1st March and 31st May 2022, PLWH were invited to take part in an observational study using semi-structured interviews.
- Inclusion criteria: adults (>18 years old) living with HIV; enrolled in the SHCS; treated at the Infectious Diseases Outpatients Service of Lausanne University Hospital; French speaking.
- Exclusion criteria: active mental health issues including depression; on anti-epileptic or anti-depressant treatment; diagnosed neurocognitive impairment.
- Consenting participants attended confidential one-to-one semi-structured interviews of up to 90 minutes with trained researchers.
- Interviews were recorded and then transcribed.
- In this first stage, analyses were conducted using iRaMuTeQ. This software produces various text analyses, including discourse classification based on word frequency and co-occurrence.
- The classification generated by the software was then interpreted by members of the research team trained in qualitative methods.

Results

• 19 PLWH treated at the centre for infectious diseases in Lausanne
• 11 were women, 12 were from European countries, 13 stopped studies before high school, 16 had been diagnosed for more than 10 years, and 10 had a CD4 nadir score < 200 cell/ml.
• Mean age was 49 years.
• Analyses showed that two main themes emerged from PLWHs’ discourse:
  - Social representations of HIV (Fig. 1a)→ represented among: men, participants from European countries and participants with higher levels of education
  - Medical experience of HIV (Fig. 1b)→ emphasized among women, participants from non-European countries and participants with lower levels of education
• Each of these two categories was subdivided into five themes (see Figure 2).

Discussion and implications

- Few participants had experienced enacted stigma: in most cases this may have because they used strategies to avoid it. In other cases it was because they did not have negative reactions when discussing their status. Either way, anticipation and avoidance play a large role in daily life and organization and indeed carry more weight than experiences of enacted stigma. This paradox echoes findings in recent research which shows that while 85% of respondents think that PLWH deserve the same level of support and respect as people with any other long term health condition (indicating low stigma), 83% also think that PLWH often face negative judgement from others in society.
- The ability of PLWH and increased knowledge, for example through media discussion of HIV, could have a positive impact on public perceptions of HIV and therefore be a strategy to reduce stigma. This is supported by recent research in the field.
- Acceptance of living with HIV is perceived as a personal journey: it is necessary to detach oneself from the perceived and anticipated judgement of others. In this sense, people who have accepted living with HIV tend to see treatment as something automatic rather than a constraint; they have decided who to tell and are comfortable with this.
- Healthcare professionals and more particularly physicians hold epistemic authority: they have the medical knowledge, they are trusted, and they play a central role in the way PLWH perceive and avoid HIV stigma. There is a potential paradox here: in their concern to protect patients, physicians may perpetuate the notion that HIV must be kept secret, from the waiting room to the home. Contradicting the notion that keeping HIV secret is protective, participants in this study described how being able to discuss their HIV status could be beneficial.
- This study had limitations. The study exclusion criteria precluded access to PLWH whose discourse and experience might differ from what is presented here. Consequently, it is not possible to say whether our observations are applicable to the PLWH who were not presented in this study.
- Key message: Navigating anticipated stigma constitutes a considerable burden for PLWH, despite limited experiences of enacted stigma. Wider public discussion of HIV, particularly concerning advances in treatment and modes of transmission, could attenuate this. Healthcare professionals, often seen as an all-knowing authority, sometimes advise patients not to discuss their HIV status. Despite the good intentions behind this advice, it may be damaging rather than ‘protective’ and requires nuance: some PLWH find that talking about their HIV is beneficial and even empowering.

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References and definitions

3 Epistemic: relating to knowledge or to the degree of its validation.
4 Prototypical: is used to indicate that someone or something is a very typical example of a type of person or thing (Collins English Dictionary)
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